

Chapter 4

Detection

South Carolina Cancer
Prevention and Control

Chapter 4. Early Detection

There are more than one hundred different kinds of cancer but most share a common element: early detection can mean the difference between life and death.

Four of the most deadly types of cancer in South Carolina: colorectal, breast, cervical and prostate cancer, can all be detected at an early stage through routine, inexpensive tests. The challenge for the public health and medical communities in South Carolina is to determine how to make sure that people know about these life-saving tests and to help them break through financial, psychological, and transportation barriers to get the health care they need.

Colorectal Cancer

Colorectal cancer claims more lives in South Carolina than any other malignancy besides lung cancer, even though we have the medical technology to detect signs of this cancer long before it becomes deadly. Cancerous polyps and their precursors may be present in the colon for years before invasive cancer develops. Reducing mortality from colorectal cancer depends on detecting and removing these polyps and on treating invasive cancer in its earliest stages. (CDC, 1996a). The American Cancer Society reports that survival rates for patients with colorectal cancer could be increased from 55% to 85% with screening and early detection in conjunction with appropriate management. Three tests are currently available for colorectal cancer:

Fecal Occult Blood Testing (FOBT) tests for blood in a patient's stool sample. A positive test can indicate bleeding from a precancerous growth or from colorectal cancer.

However, FOBT has the potential for false positive and false negative results. False positive results can be caused by medical conditions or by certain drugs; false negatives can result because polyps and some cancers may not cause bleeding or may do so only intermittently. (ACS, 1997)

Sigmoidoscopy uses a hollow, lighted tube to visually inspect the wall of the rectum and distal colon. The 35cm sigmoidoscope can detect about 50-55% of polyps; the longer 60cm flexible scope is capable of detecting about 65-75% of polyps and 40-65% of colorectal cancers. (ACS, 1997)

Digital Rectal Examination (DRE) is the most commonly used screening test for colorectal cancer because it can be incorporated easily into routine physical exams, and requires no special equipment. (ACS, 1997)

Recommendations for Screening

American Cancer Society (ACS) recommends that the DRE test be performed every year after age 40; FOBT every year after age 50; and sigmoidoscopy, preferably flexible, every 3-5 years after age 50.

The US Preventive Services Task Force recommends that physicians include colorectal cancer testing with periodic flexible sigmoidoscopy and/or annual fecal occult blood testing (FOBT) in the periodic health examination of all persons aged 50 and over (CDC, 1996a).

Barriers to Detection

While there is compelling evidence that testing for colorectal cancer can find cancer at earlier and more curable stages, most Americans are not tested. National BRFSS data from 1992-1993 found that overall, 43% of the respondents reported having had a DRE during the preceding year, and only 28% reported having had a proctosigmoidoscopy during the preceding five years. Results from a 1992 National Health Interview Survey, of adults 50 and older, were even more disturbing: only 26.3% of those surveyed reported having had an FOBT; and only 9.4% reported having had sigmoidoscopy in the preceding three years. (CDC, 1996a) A preliminary review of existing studies indicates that there are four reasons why people are not receiving the early medical care they need to protect themselves from colorectal cancer:

- 1) Lack of information.
- 2) Patient reluctance.
- 3) Lack of physician referral.
- 4) Lack of financial resources.

Lack of Information. The 1992 National Health Interview Study looked at public awareness concerning colorectal cancer. The survey found that in the 50 and older age group, which is at highest risk for this cancer, nearly 17% had never heard of FOBT and 32% had never heard of sigmoidoscopy. (CDC 1996a)

Patient Reluctance. Many patients are advised of the screening recommendations but do not follow through on them. The nature of the exam itself is a barrier and generally does not raise an enthusiastic response from most patients. Second, scheduling a flexible sigmoidoscopy frequently involves a visit to another physician, if the primary care provider is not skilled at the procedure, which makes it easier for the patient to put off taking the test. (Seabrook, Pers. Comm., 1996.)

Lack of Physician Referral. Some research indicates that although physicians may agree with early detection guidelines, they may not always follow through with recommendations. In a survey conducted of North Carolina physicians, 80% of primary care physicians agreed with the ACS guidelines for screening sigmoidoscopy, but only 34% performed the procedure themselves and 27% referred patients elsewhere for the test. (NC Cancer Plan, 1996)

Lack of Financial Resources. As stated previously, fully one third of South Carolina's population is at risk of being medically indigent, with men more likely than women to be uninsured. Medicare does not currently cover screening for colorectal cancer, and SC insurers are not mandated by law to cover this type of testing.

Breast and Cervical Cancer Detection

Early detection of breast and cervical cancer can save lives. The low-dose X-ray mammogram can now detect a breast cancer smaller than a pea, at least two years before a woman or her doctor can feel a lump. At this stage, the disease is most curable – in fact, 92% of women who find the cancer early are alive five years later. But for women with cancer that has spread to nearby regions of the body, the survival rate drops to 71%; for those with cancer spread to distant parts of the body, it is only 18%. Breast cancer death rates could be decreased by an estimated 30% if women received mammograms at recommended intervals (Shapiro, 1989).

Cervical cancer could be controlled worldwide with the present level of knowledge and technology, if adequate funds and political support were channeled to it (Gusberg and Runowicz, 1991).

Cervical cancer has a relatively long preinvasive period, which can be detected by a Pap smear. The Pap test is usually done by a doctor or nurse as part of a pelvic exam. The five-year survival rate for women with cervical cancer found in the earliest stage is almost 100%; for localized cervical cancer, 88%; and for all cervical cancer patients, 66%.

Breast and cervical cancer deaths can be explained mostly by the lack of early detection of those cancers. Late diagnosis also increases health care costs. The cost of a Pap smear as part of a routine physical averages \$75 and the cost of follow-up for an abnormal smear averages \$500. Treatment at later stages can range from \$5000 up to \$22,000.

The SC Hospital Discharge Data System provides information on the total and average costs for hospitalizations for breast and cervical cancer. The average cost of a hospital stay for breast cancer in 1996 was \$9,536; for cervical cancer, \$10,398. Costs include only hospital charges, not surgeons' fees, pre-hospital tests, radiologists' fees, anesthesiologists' charges, or any of the dozens of other costs that add to a hospital bill. Average costs vary little by race or age. But the costs in dollars and in loss of life underscore the need for earlier detection and prevention efforts.

Barriers to Detection

There are several barriers which prevent older women and particularly older African-American women from taking advantage of early detection and screening methods. (AMC, 1992)

Lack of Referral. African-American women are more likely than whites to come to a physician for acute or chronic problems than for health maintenance issues. Many women who are in the health care system because of chronic problems, (diabetes, high blood pressure, or arthritis) are not appropriately referred for Pap tests or mammography.

This makes it less likely that they will be screened and more likely that disease will be diagnosed at a later stage. In addition, studies strongly indicate that physician referral positively affects patient screening practices and that many older women cite this as the key reason for getting a mammogram.

Lack of Information. Many women believe that mammograms are unnecessary unless they have symptoms. Unscreened women often do not understand the purpose of regular screening. This is especially true if they are no longer sexually active, are not having babies, and have had negative experience with the health care system. Finally, many women do not understand that their personal risk for breast cancer increases with age regardless of family history.

Psychological and Physical Restraints. Many poorer women refuse to practice early detection because they fear cancer. In addition, African Americans hold attitudes that are distinct from non-Hispanics and whites in two areas — use of alternative health providers and fatalism regarding particular medical diagnosis. Some women feel that if they have a disease they would rather not know and that illness is part of God's will. Other women are simply afraid that mammography will hurt or are embarrassed to undress in front of strangers.

Lack of Financial Resources. Uninsured women and underinsured women are less likely than those with health insurance to have screening because of the cost. Medicare copayments can also be a financial barrier for low income women aged 65 and older.

Lack of Transportation and Access. Older women who live in rural areas and are immobile or live on fixed incomes are often confronted with this barrier to early detection. In many areas of South Carolina another real barrier is "health manpower shortage areas" — the actual number of providers able to deliver care is limited.

Prostate Cancer

Prostate cancer is the most commonly diagnosed cancer among American men after skin cancer and the second leading cause of cancer death in men after lung cancer. One out of every five American men will develop this cancer in his lifetime. *More men die of prostate cancer in South Carolina than in any other state in the union.*

Prostate Cancer Detection – The Controversy

The most effective test for this type of cancer, *Prostate Specific Antigen (PSA)*, a simple blood test, can identify tumors years earlier than previous testing methods. This test, when used in conjunction with the Digital Rectal Exam (DRE) has the potential to save lives. But the PSA test can only indicate the presence of a tumor in the prostate — it cannot forecast its progression. It could be years or decades before the disease begins to cause the patient harm. A key question underlying the prostate cancer debate is “Do the benefits of prostate cancer screening outweigh the potential harm?” Some researchers believe that for one third of men with prostate cancer, the disease will remain indolent and will not cause significant harm. They warn that a diagnosis of cancer will inevitably lead to treatment, with significant unwanted side effects. A national trial, the Prostate, Lung, Colorectal, Ovarian (PLCO) trial, is designed to answer key questions about the efficacy of screening. Results are anticipated in about eight years.

Table 4.1 (after Correa, 1997) summarizes where major medical groups stand on prostate cancer detection. ACS recommends that all men 50 and over undergo both a DRE and a PSA test on an annual basis. Men in high-risk groups, such as African Americans, or those with a strong family predisposition, may start at a younger age.

The US Preventive Task Force recommends against routine PSA and DRE testing for asymptomatic men at this time and the Centers for Disease Control supports this position. In contrast, the American Urological Association recommends that African-American and other high risk men start testing at 40 years, as does the National Medical Association.

These groups have placed special emphasis on African American men because *they have one of the highest incidence rates of prostate cancer in the world.* African Americans are 37% more likely to get prostate cancer than are white men. Many reasons, ranging from socioeconomic, to diet and lifestyle, to genetics have been proposed for the startling differences between African Americans and other ethnic groups. The underlying reasons why more black men die from prostate cancer are still not completely understood. In South Carolina, where black men make up 31% of the male population and black men die of prostate cancer at a rate which is more than twice the rate of white men, these questions are critically important.

The South Carolina Prostate Cancer Task Force

The Prostate Cancer Task Force was established in 1997 as part of this overall five-year plan to address prostate cancer detection issues. This Task Force was formed because of 1) the critical problem of prostate cancer in South Carolina, which leads the nation in prostate cancer deaths 2) the controversial nature of prostate cancer detection, and 3) concern about the soaring rates of prostate cancer among African American men in South Carolina.

The purpose of the Prostate Cancer Task Force was to first develop a consensus statement on what we could *agree* about concerning advocacy, public education and professional education for this cancer. A summary of the recommendations from that group follows.

Table 4.1 Prostate Cancer Screening
Where the Medical Groups Stand

American Academy of Family Physicians Men aged 50 to 65 should be counseled about the known risks and uncertain benefits of screening.	November 1996
American Cancer Society PSA and DRE should be offered annually starting at age 50 to men with a life expectancy of at least 10 years and to younger men (ie, age 45) who are at high risk.* Information should be provided about risks and benefits.	June 1997
American College of Physicians Physicians should describe the potential benefits and known harms of screening, diagnosis, and treatment, listen to the patient's concerns, and then individualize the decision to screen.	March 1997
American College of Radiology A combination of DRE and PSA levels should be used as an initial screening procedure. Use TRUS to evaluate men who have an abnormal DRE or PSA level.	1991
American Urological Association Annual PSA and DRE substantially increase early detection and are most appropriate for men age 50 and older (40 and older for men at high risk*). Such patients should be given information about these tests and given the option to participate in screening or early detection programs. PSA testing should continue in a healthy man who has a life expectancy of 10 years or more.	January 1995
US Preventive Task Force Routine screening with DRE, PSA, and TRUS is not recommended.	December 1995
* Men with a family history of prostate cancer and African-American men.	

SC Public Health Position Statement on Prostate Cancer

Recommendations on Early Detection

- All men must be offered information regarding the risks and benefits of detection and treatment and additional guidance should be given to men at high risk or advanced age.
- Early detection may be clinically beneficial for the majority of men, especially African-American men between the ages of 40-70 years of age, and/or any man who has two or more family members with prostate cancer.
- All men are encouraged to make individual decisions about prostate cancer testing in consultation with their private physicians.
- Men without private physicians or clear access to health care need to be a priority in prostate cancer detection efforts in South Carolina. All men at high risk for prostate cancer should have access to detection, follow-up and treatment.

To be effective, prostate cancer detection efforts must incorporate the following:

- Use of state-of-the-art PSA testing.
- Use of generally accepted diagnostic procedures recommended by the American Urological Association.
- Appropriate interpretation of prostate cancer test results.
- Patient education, so that men are able to make informed decisions regarding follow-up for abnormal findings.

Recommendations on Support for Prostate Cancer Patients

Support groups are particularly important for men diagnosed with prostate cancer because of the overwhelming number of choices that a man and his family must make when a man is facing treatment for this disease. Support groups are also important because men have not traditionally had an established healthcare pathway. Support should incorporate a variety of strategies, including:

- Advocacy for patients to be partners in their care and to be active in decision making and seeking support. The quality of care is partly determined by the quality of communication between the patient, family, and physician.
- Educational programs and materials for the patient and family to help the family understand the disease and the options available to them.
- Education for the medical community throughout South Carolina so that they are aware of the importance and availability of support groups for men who have either been diagnosed or treated for prostate cancer.
- Resources should be available for individual counseling, family counseling, and group support for prostate patients and their families.
- For men who are unable to attend conventional support groups, innovative methods for providing support, such as telephone counseling should be made available.

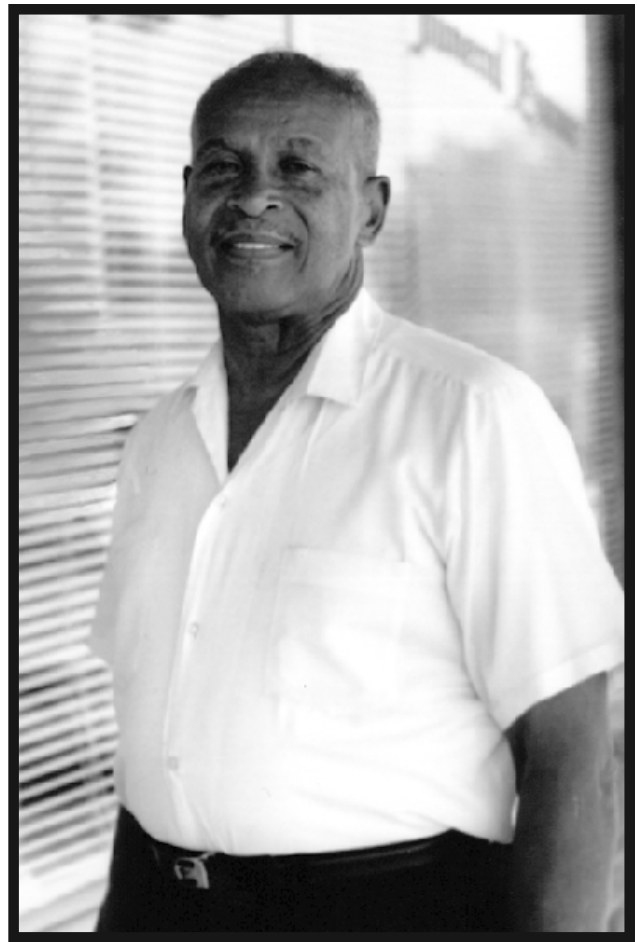
- Prostate cancer survivors and survivor's groups should be involved in developing a support network and health care pathway for men in South Carolina.

Recommendations on Advocacy

Even though a consensus does not exist in the public health community on what specifically should be done regarding prostate cancer detection and treatment, we must begin to develop solutions to this critical public health problem in South Carolina.

Resources – Resources and personnel must be available to address all aspects of prostate cancer.

Health Care and Capacity – Information on access to health care services and the quality of these services must be obtained to ensure availability and accessibility of state-of-the-art detection and treatment for all men in South Carolina.



Prostate Cancer and the African American Community

In November, 1997, “Prostate Cancer in the African American Community: An Agenda for Action” was convened in Atlanta, co-sponsored by the American Cancer Society, Centers for Disease Control and Prevention, and the National Cancer Institute and held in conjunction with the Intercultural Cancer Council, and 100 Black Men of America. The recommendations from this meeting included a call to incorporate community involvement in developing creative and innovative public education programs.

A guide issued to state health departments called for public health leaders to look at the issue of prostate cancer detection as more than a scientific issue: “We have come to realize that prostate cancer screening, like other public health issues is not only a scientific matter, but a social, political and cultural one as well. To address screening as a strictly scientific issue will risk alienating and angering a group with whom public health has an ethical and professional responsibility to build positive and useful relationships.” The guide urged state health departments to build inroads into the communities through this issue: “There is an old public health care adage: *Start where the people are*. Ideally, instead of focusing solely on the contentious details of the screening debate, health departments can work with this issue as a bridge to other pressing health problems in the African American community.” (CDC, *Preparing to Speak to Mass Media Organizations About Prostate Cancer Screening*, 1998.)

Community Leadership – Community leaders and policymakers must be educated to enable them to provide leadership. Outreach should focus on church leaders, legislators, agencies, health care providers, corporate leaders, medical universities and communities throughout South Carolina who can work together to develop solutions.

Prostate Cancer Network – A network must be created to bring South Carolinians together to address this issue.

This network should demonstrate an attitude of inclusiveness and respect, welcoming the ideas and concerns of all individuals. A central component of this network must be a grassroots, statewide effort to reach men who are poor and underserved, and have traditionally been outside the health care system. This network should empower these men to learn about their options, ask questions, be involved, make their own health care decisions, and seek the health care they need. The goal should not be to create one stance on any issue, but to share insights, culturally sensitive information, and opportunities to find solutions to the problems brought about by prostate cancer.

Cancer Genetics

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Medical genetics is moving out of the laboratory and into the mainstream. Physicians are exposed to article upon article in medical journals while patients are increasingly bombarded by sensational reports in daily newspapers and television presentations. Breakthroughs in cancer genetics are occurring faster than any other field as more research is targeted toward uncovering the mysteries of the genetic code behind such common malignancies as breast cancer and colorectal cancer.

Most cases of cancer occur by chance in individuals who do not have a family history of cancer. Although all cancers are genetic, only about 5-10% are thought to be inherited. Another 10 to 15% are thought to comprise both hereditary as well as environmental factors, while the remainder are thought to occur sporadically. Table 4.2 illustrates our current understanding on individual cancers and genetic factors.

Table 4.2. Cancer Genetics

Cancer	Genetic Marker	Percentage Due to Hereditary Factors
Breast Cancer	BRCA1/ BRCA2	5-10%
Colorectal Cancer	MSH2, MLH1, PMS1,2, APC	15-20%
Prostate Cancer	HPC1	5-10%
Ovarian Cancer	BRCA1/BRCA2	5-10%

Cancers with Genetic Markers

Breast and Ovarian Cancer. Identification of the BRCA1 and BRCA2 breast and ovarian cancer genes has made physicians, and the women they treat more aware of how family history can affect a person's risk for developing cancer. Breast cancer is the most common cancer in women. The chance that a woman who lives to the age of 85 will develop breast cancer is 1 in 9 (11%). Ovarian cancer is much less common than breast cancer with a 1 in 70 (1-2%) lifetime risk for women in the United States.

Most cases of breast or ovarian cancer occur by chance in women who do not have any family members diagnosed with cancer. However, 5-10% of women who develop breast or ovarian cancer will have a strong family history of one or both of these malignancies.

Colorectal Cancer. Colorectal cancer is the second most common cancer diagnosed in the United States. The chances that a person will develop colorectal cancer in his or her lifetime is 6%. Approximately 15-20% of people who develop colorectal cancer will have a family history of the condition.

Prostate Cancer. Prostate cancer is the most common form of cancer diagnosed in males in the United States. The chance that a man will develop prostate cancer in his lifetime is 9.5%. An aging population, as well as improving detection methods, continues to make prostate cancer a common malignancy. As with other cancers, most cases of prostate cancer occur by chance in individuals who do not have any family members diagnosed with prostate cancer. However, 5-10% of men who develop prostate cancer will have a strong family history of this malignancy.

Genetic Counseling

For some people, having a family history of one of these four cancers means that they have a high chance of developing one of these cancers, and in some cases, other cancers as well. Cancer runs in these families due to an inherited mutation in a single cancer-disposing gene. This is called hereditary cancer.

Identifying individuals at increased risk for hereditary cancer begins by constructing a three-generation, cancer-targeted pedigree and/or asking very structured questions regarding the family history. The purpose of pedigree analysis/family history assessment is to look for characteristics of hereditary cancers. If a family history is suggestive of hereditary cancer, the next step is to refer the patient for genetic counseling and cancer risk assessment. Genetic counseling for genetic risk assessment is a service which involves translating basic genetic concepts into an understandable form of information for patients, confirming family histories via medical record documentation for cancer diagnoses, discussing the nature and magnitude of cancer risks, reviewing the benefits, risks and limitations of cancer genetic testing, and recognizing the psychosocial impact of cancer risk assessment.

When a family history does show a pattern of hereditary cancer, then genetic testing may be an option. These blood tests allow scientists to look directly at specific genes for cancer-causing mutations. It is often necessary to have a blood sample from a family member with cancer in order to participate in genetic testing. This test cannot rule out the possibility of ever developing any cancer. Yet, within a hereditary cancer family, it can identify those individuals at higher risk (i.e., those who inherited the mutated cancer gene) versus those whose cancer risk is not increased.

The goal of genetic counseling is to make families aware of their genetic risk. Sometimes, people learn that their cancer risk is less than they expected. Yet it is also important to identify people who may have a higher chance of developing cancer so that these individuals can be followed carefully by their physicians. Possible medical management strategies include increased cancer screening, guidelines for nutrition and exercise, prophylactic surgeries, and chemopreventive agents. The ultimate goal is early cancer detection or prevention.

Cancer Genetics and Public Policy

Advanced genetic testing gives us a screening tool which can be used before cancer has even had a chance to develop. For individuals who carry a genetic marker for cancer predisposition, clinicians can recommend surveillance and possibly aggressive surgery. This new technology has the potential to save lives. At the same time, these advances open an ethical frontier for clinicians, public health professionals and legislators. Without clear legislative protection, patients could potentially become uninsurable if their medical records carry documentation for the genetic predisposition of certain cancers. These issues, which are unprecedented, must be dealt with legislatively to ensure that South Carolinians are protected as new molecular biologic techniques are introduced.